

Zero-to-NEWS Three

from the Early Intervention Section,
Hawaii State Department of Health

Vol. XIII, No. 1

Spring 2003



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The Early Intervention Section of the State Department of Health provides developmental services for any eligible child from birth to three years of age in five areas: physical, cognitive, communication, social or emotional, and adaptive.

Services are available on all islands and there is no cost to families.

For more information, please contact our Hawaii Keiki Information Services System (HKISS) referral and information line at 973-9633 for Oahu and 1-800-235-5477 for Neighbor Islands.

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A Family's Quest

Melanie Simmons was born a bit earlier than expected—she was premature. Born at 24 weeks gestation, she was approximately a foot in length and weighed about 1-½ lbs. She was barely bigger than the palm of her father's hand.

Generally, premature births include babies born earlier than 37 weeks and/or have a low birth weight (less than 5 ½ lbs.) Nationally, the number of premature births has



increased 27% from 1981 to 2001 and is considered the highest in 20 years. In 2001, 12.8% of all Hawaii

births were premature which was higher than the national rate of 11.9%.

When premature babies are born, more life support is needed for survival than what mothers can biologically provide. Depending how premature the birth is, organs such as the lungs, heart, brain and intestinal tract may not be developed enough to function independently. Premature babies are also at higher risk of having developmental delays.

With medical advances and treatment today, however, the survival outlook for babies like Melanie is improving. Despite this positive trend,

nothing can prepare a parent mentally and physically in caring for a premature baby.

Pat Simmons, Melanie's mother, recalls the days following Melanie's birth as a very frightening experience. "My due date was September 1, 2000 and I gave birth on May 15, 2000... We stayed at the hospital at the neonatal intensive care unit (NICU) for 2 ½ months and we were discharged. We were readmitted about 3 days after because she was having excessive vomiting and APNEA (where she just stopped breathing...) and was turning blue," states Simmons.

Simmons felt Melanie was discharged too early despite meeting the hospital and insurance criteria: maintaining her body temperature outside the incubator, drinking from a bottle over a 24-hour period, and breathing on her own with the assistance of 24-hour oxygen. She and her husband also felt unprepared in



how to care for Melanie. Simmons shared, "...they readmitted her and she was in

intermediate (nursery) for two more weeks...it was amazing in two more weeks, how much more stable she was...even the respiratory therapist was saying 'wow'". A relieved Simmons was also grateful for the training she received on how to care for Melanie. "It's nothing like having a

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CHAIR'S MESSAGE

by Jennifer Schember-Lang

Marge Piercy in her poem "To be of use" speaks of people who "jump into work head first without dallying in the shallows." She speaks of those who "harness themselves, an ox to a heavy cart, who pull with massive patience, who do what needs to be done again and again." She writes that "things that are worth doing well done have a shape that satisfies, clean and evident."

I am reminded of this poem when I think of systems change and improvement efforts. How can we (families, program staff, administrators, and yes, advocates) all work together (again and again, if necessary) to ensure the early intervention system in Hawaii is *comprehensive, easy to access,*



understandable, sensitive to family needs, values and structure, family-centered, and providing quality services. These were among the words and phrases important to members of the Hawaii Early Intervention Coordinating Council (HEICC) in strategic planning sessions conducted in 2002. We must remember this as the HEICC assists the Department of Health (DOH) in the (1) development of policies, (2) achievement of full coordination and cooperation of all appropriate public agencies, (3) effective implementation of the statewide system by seeking information about policies that impede timely service delivery, and (4) resolution of disputes. The HEICC also advises DOH and the Department of Education on the provision of services for children ages birth to five.

The HEICC membership includes a broad cross section of the early intervention community including parents, state legislators, state agency

personnel, state education agency personnel, a representative from the agency responsible for state health insurance, a representative from the Governor's Office, a member from a Head Start agency, and residents from the neighbor islands. Regular meetings are held in Honolulu and are open to interested members of the public.

Among the tools HEICC members and others might use to improve our statewide system is the Part C Update, a report from the National Early Childhood Technical Assistance Center (NECTAC). This report is about various aspects of the Early Intervention Program (PART C of the IDEA). The intent of the Part C Update is to collect, in a convenient format, a variety of resources that meet the information needs of states, Part C program staff, the U.S. Department of Education and policymakers at all levels. It includes the Twenty-third

(continued on page 3.)



JUST ASK MIKE

Dear Mike: People tell me I need to take some time for myself. I think I need to wait until my child is older. What do you think?

—Stressed Parent

Dear Stressed Parent: Taking care of children requires great amounts of time, energy, money, knowledge, as well as a caring heart. Being a parent is one of society's most stressful jobs. It is important to take time for yourself. Below are a few ideas for managing stress:

Stress Busters

1. Get a good night's sleep. Lack of sleep makes us vulnerable to the consequences of stress.

2. Start your day by doing something nice for yourself. Make a list of things that make you happy. Then do something on that list, e.g. Listen to a favorite CD, have a special snack.

3. Eat, drink and be healthy! Eat a wide variety of healthy foods. Drink plenty of water.

4. Get physical! Do an activity you enjoy, e.g., hiking, swimming, or dancing. Regular exercise helps maintain a healthy body, reduces stress, and promotes sound sleep.

5. Breathe deeply! Take breaks. Let your mind and body relax periodically during the day. Enjoy lunch!

6. Take at least a half hour to do something relaxing in the late afternoon or early evening.

7. Spend time with people in your life who are important to you, are good companions, and care about you.

8. When visiting with friends and family, be sure to share things in your life that are of concern to you.

9. Consider minimizing contact with people who are negative or unhealthy influences in your life.

10. Finally, each night before you go to bed, do something you enjoy, even if it is only for 10 or 15 minutes. For example, a colleague of mine writes a gratitude journal. She lists 5-10 things, that she was grateful for each day.

So, until next time, take good care of yourself.--Mike

Got a question? Write to Mike at the Early Intervention Section, 1600 Kapiolani Blvd., #1401, Honolulu, Hawaii 96814.

(Mike Compton is a psychologist with the Early Intervention Section. He is a parent of three children.)

Profile:

Dr. Chiyome Fukino, MD State Director of Health

Dr. Chiyome Leinaala Fukino is the first woman to head Hawaii's Department of Health (DOH). She



was an original member of Governor Lingle's selection committee and when the other members

saw her curriculum vitae, they asked if she would consider the job.

A friend said this was a great opportunity to 'make a difference,' something Fukino had always aspired to do.

It was a difficult decision. It meant that Fukino would close her practice after 20 years. As Fukino comments, "I enjoyed that part of medicine...the patients and the patient relationships—I found that very rewarding."

However, she could not do both—seeing patients and directing a department consisting of 3 administrations, 11 divisions, and over 3,000 employees. As expected, life has not slowed since she took over the Director's job. She has hit the ground running, quickly learning about unfamiliar areas such as environmental health and the legislative process.

She anticipates the pace will not slow after the legislative session especially when the department begins grappling with a reduced budget. "How do we organize the department to manage efficiently... and streamline—what does that mean... We are going to revisit our core priorities and decide how we are going to allocate funds. If you have a pot of money...what percentage of that pot will go for direct services vs. preventive, education type services...DOH is really a body that

does broad-based preventive type services or services not covered in the private sector," says Fukino.

What of early intervention services? Fukino states, "What you do to your babies and little keikis is going to affect how they grow up...what is the core service (early intervention) that we are going to provide and how much staff do we need to do a good job. And we have to maintain that baseline level of personnel...you keep on giving more

Career Highlights

Private Practice
Medical Director, Queen's
Physician Group
Consultant to Kahi Mohala

Education

University of Hawaii,
John A Burns Medical School
Brandeis University
Kamehameha Schools

work to people and they burnout...become ineffective...we have to clearly look at our resources and define what we are going to do..."

Fukino believes that DOH may not be able to provide some direct services unless outside funding is obtained. She stated, "...We have to teach and re-educate the public...that we need to take and assume more personal responsibility for ourselves, our children, our families, and for our communities because government alone cannot afford to pay for all of this. Our department's focus should be to provide services for the most vulnerable populations that are not filled by our private sector. We have to encourage people and the private sector to take more responsibility and do it well so we can do our job."

The streamlining process within DOH has already begun and Fukino hopes much of it will be done before the next legislative session. Does she have any spare time? Somewhere between all these activities, this recent newlywed intends to go whale watching with her husband. She explains, "I've never actually seen whales in the ocean. I have seen them from the shore. This year, we're going to watch whales!"

(Chair's Message--cont. from page 2.)

Annual Report to Congress on the Implementation of the IDEA (2002) and a chapter on characteristics of children and families entering early intervention.

Since the HEICC is charged with making recommendations to the governor, the legislature, and the state we welcome your comments and will continue our efforts to be 'of use' to children and families in Hawaii.

Part C Child Count and HKISS Referrals

As of December 1, 2002, 4,999 children were served by Part C early intervention services in Hawaii. An increase of 26% or 1,038 more children were served compared to the 2001 count. More specifically, 2,997 children were identified as at-risk for delay and 2,002 children were developmentally delayed.

	#Served	#Increase	%Increase
DD*	2,002	312	18%
At-Risk	2,997	726	32%
Total	4,999	1,038	26%

*Developmentally Delayed

Additionally, the number of referrals to the Hawaii Keiki Information Service System (HKISS) has increased by 25%. In 2002, HKISS had 1,241 referrals compared to last year's 992. This count only includes the number of referrals made to HKISS and does not include the referrals made directly to our Early Childhood Services Programs or private providers that also offer early intervention services.

Randy's World by Randy Compton



(A Family's Quest--cont. from page 1.)

normal child," she commented.

Simmons has another daughter who is four years old.

Having a medically fragile child, Simmons was able to access medical insurance to provide some skilled and respite nursing at home when Melanie was discharged. She has had to fight for some of these services and support. When the nursing services did not have a respite nurse, Simmons recruited her own nurse. When informed by her insurer that respite services would be cut when Melanie turned one, Simmons became much more assertive in advocating for Melanie. The insurer converted some benefits and continued her respite care for another three months. And finally, when told that she may not qualify for the Medically Fragile Infant Medicaid Waiver program, she applied anyway and although denied, she eventually got assistance through the Nursing Homes Without Walls Medicaid Waiver program.

Meanwhile, Melanie was also receiving physical therapy (PT) at the hospital for low muscle tone. Upon discharge, Melanie was referred to the Early Intervention Section (EIS) and Kapiolani Mobile Team was sent to provide PT services at home. Simmons was also informed that she might want a public health nurse (PHN) to monitor Melanie's care and progress. After contacting a PHN, Simmons was informed that Melanie was also eligible for additional respite services through EIS.

While Simmons is very happy with the services provided by her PHN, the Nursing Homes Without Walls, and EIS (e.g., Kapiolani Mobile Team), the journey has certainly not been easy. In addition to working with Melanie's fragile physical state, Simmons had to take leave from work. She and her husband often wondered if they would lose their home because of the high medical costs. She reflects, "you get more empowered by this experience...all you can do is rely on yourself."

Melanie, amazingly, has and continues to do well. Through EIS she has also received occupational and speech therapy and is a thriving little girl. She continues with the 24-hour oxygen and is fed through a gastrostomy (tube-fed). Simmons describes her, "She's a real rascal, she likes to color and paint. She is active, nonstop until she goes to bed. She likes to dance. She still needs to build her chewing and swallowing skills. I don't know why, she still gags a lot."

And mom? Simmons has since returned to work on a part-time basis. She has also agreed to be a family representative on the Hawaii Early Intervention Community Council (HEICC). The HEICC oversees EIS services statewide. When asked why she chose to serve with the HEICC when her schedule is so busy, Simmons simply said, "I really want to make it better for the next family."



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